

# Muscular Dystrophy Foundation

## Annual Report 2012 - 2013

### Chief Executive Officer's Report

Throughout the financial year 1 July 2012 to 30 June 2013 the Muscular Dystrophy Foundation operated under the priorities and strategies considered within the planning sessions in late 2011 and early 2012.

Mission- Promise for Today.

Vision- Help for today and tomorrow.

Values- Determined, Innovative, Passionate, Embracing.

### 1. Advocacy

Throughout the year I have assisted in the progress of a Neurological Alliance Australia (NAA). This group has representation from ten organisations working within the neurological and neuromuscular areas. Initial work focused on the need for a prioritized agenda for lobbying national government. This resulted in a successful campaign to have the relevant conditions recognised within the NDIS planning framework

Priorities are:

- Support for early intervention services to reduce the economic and social burden and improve quality of life.
- Development of evidence based data to inform economic and social arguments.
- The need for disease sensitive assessments and appropriate review processes.

In December 2012 a position statement for NAA was finalized with agreement from all parties.

On behalf of Muscular Dystrophy Foundation I assisted in the development of a joint submission into the Senate hearing on the National Disability Insurance Scheme Bill.

In the period from July to December 2012 I met with five members from the House of Representatives and five Senators to lobby for the inclusion of the family support program "better start". The lobbying did not directly result in an increase to families with Muscular Dystrophy. The program is however being incorporated into the NDIS and will be accessible to children living with Muscular Dystrophy.

Throughout the year the CEO's of each partner association have met on a regular basis by teleconference and face to face on one occasion. These forums have enabled implementation of the actions detailed above and to debate numerous challenges as the disability landscape changes.

## 2. Research

Work continues toward the development of a collaborative strategy on research. Close collaboration between Muscular Dystrophy WA, Muscular Dystrophy SA and Muscular Dystrophy Foundation on the development of this initiative, and maintenance of a close working relationship with the Australian Neurological Network.

As an associate researcher on the ANN/CRE initiative and as a member of the executive committee I continue to represent Muscular Dystrophy Foundation in these deliberations.

An absence of surplus funds has reduced the need for a three year set of priorities however we are developing strategic priorities for partner consideration.

Muscular Dystrophy Foundation was pleased to sponsor some key aspects of the World Muscle Congress in Perth (October 2012). John Gummer provided the welcome speech on behalf of the Foundation

## 3. Service Delivery.

The agreed strategy to raise national awareness of state based client service delivery opportunities and programs has been implemented.

- Duke of Edinburgh-Facilitation through NSW. Policy and Procedure documents shared with partner associations. NSW supported in application for national license.
- Little Heroes care-facilitated through South Australia. Funds distributed for client support in South Australia, Queensland and New South Wales. \$300,000 distributed in this financial year and across financial years \$500,000.
- Conference riding the wave-. Muscular Dystrophy Foundation was pleased to sponsor the Queensland led initiative, client and practitioner focused conference "Riding the Wave. Sponsorship \$10,000 and staff attended for support.

ACT negotiations and support to new group - Extensive negotiations with (ex partner) Muscular Dystrophy ACT to aim to re establish membership and establish some coherent service strategies in ACT. Negotiations terminated late in the process by Muscular Dystrophy ACT.

Subsequent support provided to interested parties in ACT to establish an organisation to support clients in this area.

## 4. Brand

Implementation of the agreed strategy to have a consistency appearance through web sites, logo, letterhead and materials has been successful with all being similarly branded.

The strategy to have consistent Mission and Vision is approximately 60% implemented.

Marketing materials have been produced for television advertising and distribution to potential sponsors and partner organisations

## **5. Events**

By July 2012 it was evident that the objective to implement national fundraising initiatives was continuing to create concerns within state jurisdictions and at an operational level within Muscular Dystrophy Foundation. Muscular Dystrophy Foundation had already ceased involvement with ASX Reuters Charity Foundation as it was believed the focus of this support was more appropriately focused on supporting the Duke of Edinburgh initiative within Muscular Dystrophy NSW.

Similar concerns were being raised about the Tour Duchenne Bike ride as most participants were from two states and the funding model did not assist sustainability. Muscular Dystrophy Foundation proceeded with the 2012 ride and has subsequently acted to terminate the joint venture agreement.

An initiative in conjunction with Fire fighters in 12 jurisdictions was completed in the latter part of 2012 reviews of the model confirmed significant challenges in implementing a project of this size and scope from a small office. The model has now been altered to encourage localized initiatives through state associations with clear links to client outcomes. A percentage of funds raised will be made available to Muscular Dystrophy Foundation for awareness and advocacy.

## **6. Governance**

In November 2012 the CEOs recommended, and the Muscular Dystrophy Foundation Board accepted, a proposal to introduce a Governance and policy support system (Compli Space Fundamentals). This suite of programs were progressed through the year and concerns about state autonomy resolved. The program is currently being implemented.

## **7. Admin & Finance**

Throughout the year considerable time has been spent evaluating the range of models which Muscular Dystrophy Foundation has aimed to implement. The historical assumptions regarding revenue raising and distributions were assessed and a new model developed. The Muscular Dystrophy Foundation is in the process of determining its primary areas of focus. Early feedback indicates strong support for advocacy & lobbying, Research and consistency of client protocols. There is no expectation that Muscular Dystrophy Foundation will automatically distribute funds to partner entities. Discussions are progressing to clarify funding sources and implications.

Protocols to clarify procedures for fundraising activities have been developed and implemented. These were particularly beneficial for 'fill the boot' fundraising and have been maintained for current activities.

Staffing changes and contract terminations have been implemented in accordance with this direction. The staffing levels have been reduced from 3.8 FTE to 0.6 FTE

Phil Martin  
Chief Executive Officer

## Chairman's Report

The board met on July 5 and 6, 2012 and agreed on a risk strategy and that the board should be broadened during the year to include if possible an independent chairman, and an increase in independent directors with skills which would benefit the board. Soon afterwards Peter Debnam joined the board as the MDNSW representative director.

The Partnership Agreement providing a road map for the relationships between state members and MDF was finally agreed upon, with the exception of the Marketing & Fundraising areas.

It was agreed that the Tour Duchenne 2012 and Fill The Boot fundraising programs would proceed, the latter with the support of most State Fire Services.

These two events required intensive effort from 3 FTE and the cost of running a Sydney office, a major resource commitment for a small organisation, which the board considered unjustified. In February the decision was made to close the Sydney office and relocate to Adelaide where the CEO Phil Martin resides. I thank MDASA for providing office space for us at no cost, along with our Sydney partner Compli Space, who provide office space for us in Sydney for Debbie Nicholson and Phil Martin on a part time basis.

David Mathlin, an independent director, who joined the board in April, was invited to update the role of MDF, which he did with a Business Plan, which was eventually approved by all states. This plan emphasises the importance of Advocacy, particularly with Federal Government, membership of key neurological alliances, research direction and marketing on behalf of member states. Fundraising under this plan is to be directed to National Corporates, Foundations and Trusts, and with support of events organised by third parties, not by MDF itself.

The Governance and Finance Committee chaired by Sandra Di Blasio (SA) and including Rob Storey (WA) vetted all financial results provided to the board during the year, and a Sponsorship Committee was formed in May, to identify national corporate and grant opportunities. This Committee, chaired by Rob Ferguson (NSW) and including David Mathlin(NSW) and Peter Debnam (NSW) were ably assisted by Phil Martin, as is the Governance and Finance Committee.

Anne Ashford (TAS) graciously accepted the role of company secretary which she has performed admirably, recently advising our obligations under the newly formed ACNC (Australian Charities and Not For Profit Commission).

Brian O'Sullivan who chaired MDF from 2007 – late 2011 made a very generous \$50,000 donation via his company in June.

I wish to thank board members for their continuing participation and support this year. I particularly thank Phil Martin our dedicated CEO who has shown enduring commitment. Phil has been ably supported by Debbie Nicholson in providing excellent financial advice and accounts.

Rob Ferguson  
Chairperson